



## Complete Summary

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### **GUIDELINE TITLE**

Best evidence statement (BEST). Inpatient support groups for families of children with intractable epilepsy.

### **BIBLIOGRAPHIC SOURCE(S)**

Cincinnati Children's Hospital Medical Center. Best evidence statement (BEST) inpatient support groups for families of children with intractable epilepsy. Cincinnati (OH): Cincinnati Children's Hospital Medical Center; 2009 May 13. 5 p. [12 references]

### **GUIDELINE STATUS**

This is the current release of the guideline.

## COMPLETE SUMMARY CONTENT

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METHODOLOGY - including Rating Scheme and Cost Analysis  
RECOMMENDATIONS  
EVIDENCE SUPPORTING THE RECOMMENDATIONS  
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## SCOPE

### **DISEASE/CONDITION(S)**

Intractable epilepsy

### **GUIDELINE CATEGORY**

Assessment of Therapeutic Effectiveness  
Counseling

### **CLINICAL SPECIALTY**

Family Practice  
Neurology  
Pediatrics

## **INTENDED USERS**

Advanced Practice Nurses  
Nurses  
Physician Assistants  
Physicians  
Psychologists/Non-physician Behavioral Health Clinicians  
Social Workers

## **GUIDELINE OBJECTIVE(S)**

To provide recommendations for the use of inpatient mutual support groups for families/parents of children with intractable epilepsy

## **TARGET POPULATION**

Parents of children age 0-18 years hospitalized with intractable epilepsy

## **INTERVENTIONS AND PRACTICES CONSIDERED**

Development of inpatient mutual support groups for families/parents of children with intractable epilepsy

## **MAJOR OUTCOMES CONSIDERED**

Parental anxiety/stress levels, attitude and knowledge

## **METHODOLOGY**

### **METHODS USED TO COLLECT/SELECT EVIDENCE**

Searches of Electronic Databases

### **DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE**

#### **Search Strategy**

OVID Medline, OVID CINAHL, OVID EBM Reviews, PubMed, Scopus, PsychInfo, NACHRI list serve, and hand searching the selected articles for references

Search terms included families, psychosocial stress, intractable epilepsy, intervention, advocacy, inpatient support groups, family satisfaction, coping mechanisms, perception, seizures, pediatric

### **NUMBER OF SOURCE DOCUMENTS**

Not stated

## **METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE**

Weighting According to a Rating Scheme (Scheme Given)

### **RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE**

#### **Table of Evidence Levels**

<b>Quality Level</b>	<b>Definition</b>
1a† or 1b†	Systematic review, meta-analysis, or meta-synthesis of multiple studies
2a or 2b	Best study design for domain
3a or 3b	Fair study design for domain
4a or 4b	Weak study design for domain
5	Other: General review, expert opinion, case report, consensus report, or guideline

† a = good quality study; b = lesser quality study

**Note:** Full tables of evidence grades and strength of recommendations are available in separate documents (See "Availability of Companion Documents" field).

## **METHODS USED TO ANALYZE THE EVIDENCE**

Systematic Review

### **DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE**

Not stated

## **METHODS USED TO FORMULATE THE RECOMMENDATIONS**

Expert Consensus

### **DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS**

Not stated

### **RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS**

#### **Table of Recommendation Strength**

Strength	Definition
"Strongly recommended"	There is consensus that benefits clearly outweigh risks and burdens (or visa-versa for negative recommendations).
"Recommended"	There is consensus that benefits are closely balanced with risks and burdens.
No recommendation made	There is lack of consensus to direct development of a recommendation.
<b>Dimensions:</b> In determining the strength of a recommendation, the development group makes a considered judgment in a consensus process that incorporates critically appraised evidence, clinical experience, and other dimensions as listed below.	
<ol style="list-style-type: none"> <li>1. Grade of the Body of Evidence</li> <li>2. Safety/Harm</li> <li>3. Health benefit to the patients (direct benefit)</li> <li>4. Burden to patient of adherence to recommendation (cost, hassle, discomfort, pain, motivation, ability to adhere, time)</li> <li>5. Cost-effectiveness to healthcare system (balance of cost/savings of resources, staff time, and supplies based on published studies or onsite analysis)</li> <li>6. Directness (the extent to which the body of evidence directly answers the clinical question [population/problem, intervention, comparison, outcome])</li> <li>7. Impact on morbidity/mortality or quality of life</li> </ol>	

**Note:** Full tables of evidence grades and strength of recommendations are available in separate documents (See "Availability of Companion Documents" field).

## COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

## METHOD OF GUIDELINE VALIDATION

Peer Review

## DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not stated

## RECOMMENDATIONS

### MAJOR RECOMMENDATIONS

The strength of the recommendation (strongly recommended, recommended, or no recommendation) and the quality of the evidence (1a-5) are defined at the end of the "Major Recommendations" field.

It is recommended that mutual support groups for parents/families of vulnerable pediatric patients (i.e., children with intractable epilepsy) in the inpatient care setting be developed, implemented and evaluated (Anderson-Butcher, Khairallah, & Race-Bigelow, 2004 [4b]; Aytch, Hammond, & White, 2001 [4b]; Lewis et al., 1991 [2b]; O'Brien, 2002 [4b]). The evidence demonstrates that parent support groups can:

- Improve parental attitudes
- Increase parental knowledge
- Decrease parental anxiety

**Note:** An evaluation of mutual support groups would include a measurement of the intervention's effectiveness and address any potential adverse effects.

## Definitions:

### Table of Evidence Levels

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**Note:** Full tables of evidence grades and strength of recommendations are available in separate documents (See "Availability of Companion Documents" field).

### CLINICAL ALGORITHM(S)

None provided

## EVIDENCE SUPPORTING THE RECOMMENDATIONS

### REFERENCES SUPPORTING THE RECOMMENDATIONS

[References open in a new window](#)

### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence is specifically stated for the recommendation (see "Major Recommendations" field).

## BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

### POTENTIAL BENEFITS

#### *Health Benefits*

Increased social support, stress relief, and positive attitude change for parents and families participating in this specific intervention. Further literature goes on to report improved/increased knowledge including seizure management as well as decreased anxiety.

### POTENTIAL HARMS

#### *Side Effects*

A possible adverse effect of a parent support group may occur if it is not effective in providing the support and attention needed. Some factors that may cause this

includes how the support group is facilitated, as well as the overall environment of the meeting.

#### *Other Risks*

Other risks to consider includes cost for the support group (i.e., location, staff), time involvement of both staff and parents, ability of parents to be able to attend the meetings, and if they are able to have that devoted time away.

## QUALIFYING STATEMENTS

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This Best Evidence Statement addresses only key points of care for the target population; it is not intended to be a comprehensive practice guideline. These recommendations result from review of literature and practices current at the time of their formulation. This Best Evidence Statement does not preclude using care modalities proven efficacious in studies published subsequent to the current revision of this document. This document is not intended to impose standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to this Statement is voluntary. The clinician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.

## IMPLEMENTATION OF THE GUIDELINE

### DESCRIPTION OF IMPLEMENTATION STRATEGY

The plan to disseminate the evidence and implement a practice change of includes initial steps of providing education to appropriate staff and the unit's Family Centered Care committee. Education will include a synthesis of the evidence found to support the intervention of an inpatient parent support group. Also included in the education will be some of the components that facilitate an effective support group based on the evidence found. The plan also includes the development of an evaluation tool for staff and the committee to complete regarding the education of the proposed intervention (inpatient parent support group). Institutional Review Board (IRB) proposal will need to be accepted if an evaluation tool is developed for the education of staff.

## INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

### IOM CARE NEED

Getting Better

### IOM DOMAIN

Effectiveness  
Patient-centeredness

## IDENTIFYING INFORMATION AND AVAILABILITY

### BIBLIOGRAPHIC SOURCE(S)

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### ADAPTATION

Not applicable: The guideline was not adapted from another source.

### DATE RELEASED

2009 May 13

### GUIDELINE DEVELOPER(S)

Cincinnati Children's Hospital Medical Center - Hospital/Medical Center

### SOURCE(S) OF FUNDING

Cincinnati Children's Hospital Medical Center

### GUIDELINE COMMITTEE

Not stated

### COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

*Group/Team Members:* Gail Sextro RN BSN, A7 Neuroscience Unit; Karen Burkett MS, RN, CNP, Evidence Based Practice Mentor

### FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

### GUIDELINE STATUS

This is the current release of the guideline.

### GUIDELINE AVAILABILITY

Electronic copies: Available from the [Cincinnati Children's Hospital Medical Center](#).



Print copies: For information regarding the full-text guideline, print copies, or evidence-based practice support services contact the Children's Hospital Medical Center Health Policy and Clinical Effectiveness Department at [HPCEInfo@chmcc.org](mailto:HPCEInfo@chmcc.org).

## **AVAILABILITY OF COMPANION DOCUMENTS**

The following are available:

- Judging the strength of a recommendation. Cincinnati (OH): Cincinnati Children's Hospital Medical Center; 2008 Jan. 1 p.
- Grading a body of evidence to answer a clinical question. Cincinnati (OH): Cincinnati Children's Hospital Medical Center; 1 p.
- Table of evidence levels. Cincinnati (OH): Cincinnati Children's Hospital Medical Center; 2008 Feb 29. 1 p.

Print copies: For information regarding the full-text guideline, print copies, or evidence-based practice support services contact the Children's Hospital Medical Center Health Policy and Clinical Effectiveness Department at [HPCEInfo@chmcc.org](mailto:HPCEInfo@chmcc.org).

## **PATIENT RESOURCES**

None available

## **NGC STATUS**

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